

Questions Submitted by Webinar Participants 2/26/2014

The following questions were submitted during the webinar presentation but were not answered due to time constraints. Each question was later answered by our speakers, Dr. Susan Wiley and Michael Scott.

1. Along with the need for functional communication, can you please restate the "priority" of skills for DHH/ASD treatment? When you have an older child (10) with no language, behaviors (some violent), and academics??

This question was also discussed during the professional focus group. The autism professionals indicated interests in severity scales for ASD. Below is a table describing how DSM-V strives to rate severity levels for children with ASD.

Table: Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or

	<p>person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.</p>	<p>action.</p>
<p>Level 1 "Requiring support"</p>	<p>Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.</p>	<p>Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.</p>

Reference: <http://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria>
(accessed 2/27/14)

That being said, prioritizing skill acquisition for a child with the dual diagnosis needs to be considered from the perspective of the child and family with guidance by the professional team. Many issues can be inter-twined. One can view behavior as communication, as there is nearly always some purpose behind a behavior. However, that perspective may be an over simplification in the setting of certain biology driving behavior (such as sensory needs, obsessive compulsive behaviors or anxiety, and attention span and motoric activity).

When children do not have a formal communication system, they rely on behaviors to indicate their needs and desires. Biting, hitting, and self-injury can be a very effective way to say no or to seek out attention. Behavioral approaches use a functional behavioral assessment to try to determine the reason for behaviors and what may be happening in the environment to reinforce the behavior (or encourage the behavior to continue). Some common foundational behavior functions include "escape" (trying to get out of, avoid, or delay something they have been asked to do), "tangible" (the child gets something they wanted or delays removal of a preferred item), "attention" (the child gets more attention for misbehavior than for good behavior), and "automatic" (the child does something because it feels good). When observing behaviors, it is helpful to look for common triggers, things in the environment (including people) which makes a behavior continue. Then, one can start looking for environmental modifications to limit or avoid triggers as

well as develop consequences which may help reduce behaviors. It is also important to teach the child replacement behaviors.

Implementing a realistic and consistent approach for children with ASD can be quite effective. When behavioral strategies begin to be effective, sometimes children will have an increase in behavior before seeing improvements. This can make it easy to give up on a plan which has the potential for success over the longer time frame.

Children on the spectrum tend to respond well to visual supports and routine and structure. Another key consideration in addressing both behavior and communication is to consider a child's motivators. If a child enjoys an activity, this can become a reward for something the child does not enjoy. It may also be the activity that we see the first attempts in communication. See question 8 for more on communication development).

Within the medical setting, we often try to address the following categories of concern: Communication, sleep, toileting, behavior, family stress, medication, school concerns, social skills, medical questions, such as nutrition, dental, bowel issues. Sometimes medications can be helpful to address specific aspects of behavior. However, medication should never be the sole approach. A combination of behavior management with teaching appropriate replacement behaviors and coping strategies with targeted medication management may be needed in some circumstances.

2. Any guidance you can give itinerant teacher of the deaf that provide only pull out therapy services with students with a dual diagnosis in terms of supporting other team members?

It can be very challenging for a teacher that is not integrated (and by that, I mean working day by day, along-side others on the team at the school) into the school team and is held to "billable hours" to a school district that must be primarily in direct service to the child. If the team is open to dedicated time for case conferencing to discuss strategies to help a child move forward in their goals, this is ideal. Another approach is to overlap scheduled time with others on the child's therapeutic team. Again, this is often not how school programming is set up. If a child is in a special education or regular education setting, having time to connect with the teacher and discuss strategies related to the child's hearing loss would be optimal.

3. Any preference for mainstream or deaf residential schools as an educational setting?

It would seem that the placement of a child with the dual diagnosis depends on what skills are prioritized at the time. Priorities can change over time. This is the case for hearing children with ASD as well. Some children need a very intensive teaching setting (such as programs with applied behavioral analysis programming) to build skills and communication. Once a child can attain foundational skills, looking for broader environments to expand skill development and move up the hierarchy of communication, social skills, and learning is appropriate. Some children have mainly social-communication challenges and having typical peers is important for their growth.

It would seem the first question prior to the residential deaf school vs mainstreaming is determining if the child would be best served within a special education/autism classroom or in a program with predominately deaf education supports. The skills of professionals within each of these programs/setting will also likely vary from location to location.

Another consideration in this question is what the communication modalities are for the child. If a child is primarily signing, having appropriate sign language models for growth is critical. This is true for any child. For a child on the spectrum, the signing environment must still support their processing capabilities and may require some coaching and social skills training with peers. If peers do not understand a child's communicative intent and move on, the child will not be as inclined to initiate communication. Likewise, there may need to be some explanations to typical peers to allow them to understand why a student may be "repeating back everything I am signing."

Another important realization by educators is that even if a child has strong auditory/oral skills, sometimes the child still relies on sign language to support their listening. Many families become concerned when access to sign language/interpreters comes up as a question related to school services. Observing children in multiple settings and trying to determine what the child is relying on for success will help sustain supports which are allowing a child to perform well.

Children who have had strong auditory/oral skills may have behavioral issues with drops in hearing. Therefore, children who are deaf/HH with ASD who have behavioral changes should be evaluated for a possible change in their hearing or a change in the effectiveness of their device (such as a malfunction of a cochlear implant).

4. Are there already or could some social groups be started online (i.e. facebook type thing) so geographical issues could be eliminated?

Another participant suggested Facebook page or another avenue for sharing strategies and resources.

Families have looked to blogs and internet groups for support and guidance. It would seem professionals could do this as well. Having a point person to monitor and referee the content would be an important consideration.

If the question is focusing more on social skills development through the internet, this may provide some strategies to build a child's skills, however, face to face interaction cannot be easily replaced through electronic communication methodology.

5. Can we get contact info for the speakers?

Sure:

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6. Can you address the value of extremely structured therapies... discreet trials... and compare it to the value of teaching kids to relate to one another... social communication skills?

There are many interventions with evidence supporting their utility among hearing children with ASD. The applicability to children who are deaf/hard of hearing have not been well established. There are varying philosophical differences in these approaches. The behavioral approach (applied behavioral analysis, discrete trials) focuses on breaking down skills into small steps and directly teaching and reinforcing these skills. This approach can be quite effective for some

children, however it is important to eventually expand beyond this to ensure the skills can be generalized to settings beyond the therapeutic environment. The other important consideration in this model is to partner with professionals who focus on building an effective communication system. A communication system needs to become readily used by a child with ASD. Therefore, children need opportunities to communicate in more natural settings and experiences.

Another therapeutic approach is floor time. This perspective meets the child where they are at and tries to expand their social communication based on their interests. The interventionists meets them in their world and gradually works toward expanding broader interests.

Social skill development is another method which can help children use the communication capabilities they have for social interaction. Often social skills groups work towards understanding the basics of social communication and strive to expand a child's ability to interact with others.

A hallmark of a good program is that behavioral specialists, psychologists, speech-language pathologists, occupational therapists, and educators work together and use a broad based approach towards intervention (meaning, not one field dominates to the exclusion of other fields, but rather therapeutic interventions are complementary).

7. Can you comment on the input preferences of children with ASD--is it always the right thing to do to maximize on their audition (FM system for example, if they are learning with an aid in a classroom), or are there cases in which this could detract from learning?

Every child is unique. Every child has learning strengths. Some children are more auditory learners and others are more visual learners (even among deaf/hard of hearing children). Some children can integrate both visual and auditory input readily and others need one input at a time. Some hearing children with ASD who can describe their experiences have indicated, "when I look at you, I can't hear you and when I look away, I can hear you." This ability to "hear others" can also vary based on the environment. When children are in noisy rooms, brightly lit rooms (fluorescent lights), or highly visually distracting rooms, they may not be able to process language information as effectively.

Trying different strategies and approaches and observing how a child responds will likely guide the best scenario for a child's learning.

8. Can you please share research (citations/findings) on outcomes of CI use for children with ASD & deafness? Thank you.

One study by Donaldson has been published on children with implants who have ASD. This was a fairly small study and children had varying skills. The children were so varied, the same assessment tools could not be used. This is not necessarily surprising as children who are hearing with ASD span communication capabilities from being non-verbal to highly verbal. The publication is: Donaldson, et. al. Measuring progress in children with autism spectrum disorder who have cochlear implants. Archives of Otolaryngology Head and Neck Surgery 2004;130:666-671.

Our personal clinical experiences also span the range of outcomes for children with ASD with implants. Some children are highly successful with their implant and can persevere on

overheard conversation while others continue to rely on responding to the routine of an activity to understand what is expected of them.

When an ASD is recognized in the CI population (or children without implants), the focus of intervention tends to go back to early language foundations. If a child has difficulties with joint attention, work towards initiating and responding to joint attention becomes a necessary step for next level language to progress. Working on basic skills of turn-taking through play also establishes the concept that people are here to be with, rather than to act upon. If children can make choices between objects, this is encouraging and can be expanded to the next level of abstraction, representations of objects (such as a part of the gold fish bag with the picture).

When children realize they can request for items without relying on just getting upset or putting a person's hand on something they want, this can open up communication development. We can then work to build more levels of abstraction in the communication system, such as actual photos of objects, to line drawings to written words or sign icons. One reason photos, words, or pictures of signs can be helpful is that they remain static and the child can refer back to the representation to help process. They can also use the pictures/icons to request and eventually build sentences. The basis of Picture Exchange Communication System (PECS) builds upon this very structured turn-taking to building an expanded communication system.

9. Do you have therapeutic and/or educational recommendations for children with hearing loss/ASDs and vestibular deficits?

I am uncertain specifically what vestibular deficits means. This could include balance and motor coordination or the sensory integration perspective of difficulties with vestibular processing. Some children with ASD enjoy spinning and may not become dizzy when others would. Some children seek out this sensation. Having time to spin can be comforting and allow a child with ASD to de-stress. Children with ASD often respond well to a "sensory diet." A sensory diet intends to ensure a child has activities spread throughout the day in a pro-active manner to allow a child to focus and attend. Using a sensory room once a child is upset or having a difficult time to focus can be helpful, however the goal of a sensory diet is to implement what a child needs throughout the day in order to decrease challenges with behavior and focus.

A good occupational therapist can provide guidance on strategies to address vestibular processing as well as other sensory processing needs.

10. Have you done the research on sign language and autistic deaf kids who do not use hearing aid or cochlear implant?

Our setting does not have the expertise for studying sign language in deaf children with ASD. I would look to Gallaudet for information on that. They have had many web-based and on-site trainings.

11. How do suggest/what is the best way for parents to go about getting/requesting better training of those working with their child so that they are proficient in both PHL and ASD?

This is a big challenge for families. It seems that specialists in autism are overwhelmed by the number of children in need of services and are less likely to see children who are deaf/HH within their programs on a regular basis. Deaf educators willing to learn more about autism specific

treatments (such as getting trained on Picture Exchange Communication System, going to workshops on Behavioral Strategies for children with ASD) can build skills which can then be adapted for children who are deaf/HH. A family member can suggest specific trainings that may be relevant for their child's educational team.

Some school districts have sent teachers to additional training experiences. However the benefits of training may be limited to a time period for a specific child (as long as the child has that particular teacher). Transitions from preschool programs to elementary school to junior high to high school often bring a new team members and skill development needs to start again with a new team. Furthermore, interpreters get very little training on working with specialized populations of children. Some interpreters have a willingness and creativity to collaborate strongly with the school team. However, I have also seen situations where the interpreter was the only consistent professional for a child and essentially serving to implement nearly all activities and teaching for a child's specific goals. This is sub-optimal as the interpreter needs to be supported by the broader team rather than carry the child's programming.

I have also seen families build a powerpoint for their educational team each year, discussing their child's unique strengths and needs. This can indicate strategies which have been effective as well as indicate possible motivators to guide educational success.

12. What are your thoughts on specific ASD treatment therapies? I'm wondering if there are particular interventions that would be less optimal or more optimal as they differ greatly in their emphasis on functional communication.

Even among children who are hearing with an ASD, therapeutic strategies should be complementary to the child's needs as well as fit within the comfort of the family. Strategies may also be selected based on what is available in the area as well as the resources available. Some interventions are quite costly and can be burdensome from the amount of time in therapy.

In children who are deaf/HH with an ASD, one must also look at the ability of a program or therapeutic approach to meet the communication needs of the child. I have experienced families being excluded from very appropriate intervention programs due to the child's degree of hearing loss. The program did not realize that with a cochlear implant, the child was detecting sound at a 15 dB level. The child's lack of responsiveness was not due to hearing, but due to autism. Therefore, an ASD-specific approach would likely have been helpful had the program been willing to give a trial period.

See question 6 as well related to some specific ASD strategies.

13. I think I saw a mention of delaying intervention (hearing technology) for the sake of taking a further look into diagnosis. Can you touch upon this more because in a lot of my classes we talk about 1-3-6 and yoshinago-itano's research showing success with language development and early intervention?

I think this may have been a mis-understanding. It is absolutely essential to diagnose and intervene for hearing loss at an early age. But this journey shouldn't cause delays in the evaluation and interventions for an autism spectrum either. Some of the late identification of children with ASD seems to stem from trying one communication modality without success,

shifting to another, also without success. Then years later, the idea that a communication disorder could be the reason behind a lack of progress is finally realized. Our knowledge of children with ASD is that early is also very important. By addressing only one aspect of communication, (i.e. hearing loss), we miss a window of opportunity to address the communication disorder of ASD.

14. I would like to hear your take on Total Communication. Is this something you work towards - teaching a student to use multiple communication modalities - or is this something that the team decides once the child has been exposed to multiple modalities and has not "latched on" to a particular one?

For children who are deaf/HH with an ASD, the communication approach should be chosen based on what is being processed by the child. Just because a child doesn't seem to be looking doesn't mean they aren't processing sign or relying to some degree on lip-reading. Speech and sign are very transient. Some children with ASD need a more stable representation of language to refer to. Some families have desired auditory/oral communication for their child. Even with this goal in mind, supporting communication (see question 8) in more concrete manners can build to a higher level of abstract language (such as speech or sign).

Some children with ASD also have apraxia, or problems with motor planning. This motor planning difficulty can impact sign production and speech production. This may impact the mode for language expression. Some children need to rely on augmentative communication devices for language output. It is helpful to consider how children are taking in information (input) and how they are expressing themselves (output). This will allow the team to provide an appropriate language model for understanding language and provide strategies to allow a child to communicate. Some children understand sign well but cannot form it easily. Just because they are not using sign in an expressive manner, having access to sign language will allow them to continue to grow in comprehension. Similarly, we don't stop talking to children because they don't seem to listen. Pairing our spoken communication with visual and tangible items begins to build the relationship of what we are saying to the development of the child's language concepts.

15. Is there a questionnaire measure that pediatric audiologists can use to assist in the determination of appropriate referrals for suspected behaviors/social interactions?

This is a challenging question to answer as no screening tools have been validated on children who are deaf/HH. Although the Modified Checklist for Autism in Toddlers is a freely downloadable screening tool for autism, the way the tool is currently scored would likely over-call risk for an ASD. This tool has certain critical items which indicate a possible ASD as well as an overall item score which could also indicate an ASD. Some questions are inappropriate for deaf/HH as most would answer yes (have you ever wondered if your child was deaf?). This automatically increases the score and may put a child into the category of at risk inappropriately. Screening also takes time as well as conveying the results of screening and next steps with families.

16. Perhaps the list at the end of the slide show will answer this question but...Our eligibility committee is VERY reluctant to come up with a dual diagnoses. It almost seems that Hearing Loss precludes any other diagnoses. Is there a study that we could direct the school

psychologist, etc.

Educational settings have been problematic in the concept of a primary diagnosis which drives the IEP process. This uni-dimensional approach to program planning is a disservice to children with multiple needs. I have worked with strong educational teams who do not allow this framework to limit the goals and supports for a child.

Christy Borders in Illinois had done a study on IEP services in children within a public school district who are deaf/HH with additional learning needs. Her work has been presented, but not yet published. This study noted that children who are deaf/HH tended to increase support services as they get older. One could consider a more effective strategy would be to give more supports at earlier ages with the hopes skills will be improved and over time, less supports would need.